

"He'll never join the army"
***a report on a Down's Syndrome Association survey into
attitudes to people with Down's syndrome amongst medical
professionals.***

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This

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For Spencer Tutty

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For some time the Down's Syndrome Association has been concerned about the attitude of health professionals towards people with Down's syndrome. The findings of this survey confirm our worst fears.

It is clear that many medical staff are failing to adhere to existing guidelines and that their prejudice and ignorance is affecting the care that people with Down's syndrome are offered. It should not need to be said that people with Down's syndrome are entitled to be treated with dignity and respect and to receive the same level and quality of medical support as any other individual. General lack of respect is depressingly commonplace - this fact alone is intolerable. Horrifically though, it is clear that in some cases, lives are being put at risk.

The story of Spencer Tutty - a twenty four year old man with Down's syndrome - is just one heartbreaking example of the way that the system can fail people with Down's syndrome. We dedicate this study to Spencer and his family.

Over fifteen hundred families have contributed to this document. I hope that its findings and recommendations will be the catalyst for the change that is needed so urgently. No other family should ever have to fight for the right to medical care just because their child has Down's syndrome.

*Carol Boys
Director, Down's Syndrome Association*

Introduction

The Down's Syndrome Association has for some time been aware that not all children and adults with Down's syndrome are being afforded the same standard of care as other members of the population. As a consequence of this the DSA, for many years, has produced booklets and articles on health care issues and operated a medical advice service (see appendix 1).

In 1998 the DSA decided to send a questionnaire to all members of the DSA (see appendix 2) in order to ascertain the levels and areas of inequality in health care provision.

We received a total of 1509 responses. Of these **72%** (1083) were satisfied with the quality of care and **28%** (426) reported a high level of dissatisfaction (appendix 3).

In view of these dissatisfied responses, it can be concluded that despite a decade of government commitment to the health care of people with learning disabilities - *The Health of the Nation: a strategy for people with learning disabilities* (Department of Health 1995), *Signposts for Success* (Department of Health 1998) - change seems to be very slow.

One also has to question whether the increase in availability of pre-natal testing (see appendix 4) for Down's syndrome within the NHS has negatively influenced medical opinion and attitudes towards people with Down's syndrome.

IN THE BEGINNING

The way in which parents are told that their child has Down's syndrome can have a critical effect on their relationship with their baby (Cunningham, 1984). The diagnosis of Down's syndrome is most often made very soon after birth and before parents have had an opportunity to get to know and bond with their child. It is a time that parents remember vividly and which often colours their relationship with the medical profession from there on. Guidelines exist for medical staff to help them with the difficult task of telling parents but the response to the survey shows that in too many cases these are being ignored (see appendix 5).

After she was born, and before a diagnosis of Down's syndrome had been confirmed, I did feel that the medical staff were dealing with a "diagnosis" and not a baby - a human being. In fact a paediatric consultant offered his sincere sympathy to us. If she had been still born, then maybe such a comment would have been appropriate.

Mother of 3 year old

We were asked if we could see anything wrong with our daughter. We replied, "Yes, we know about the hair lip". "Good, good", said the doctor. "Anything else?" He then went on for about 5 minutes showing us faults and then said, "Sorry, she's got Down's syndrome".

Mother of 7 month old

The way I, a mother of a new born baby, was spoken to by the consultant paediatrician just 6 hours after the birth could have had a very devastating affect on my son. He wouldn't wait 20 minutes for my husband to join us. Then, without any tests, he used the words "could be fatal" at least 3 times. He told me there were organisations I could join but he wouldn't advise it for a few weeks as - "they were for people whose babies had died". He said, "People say you can stimulate these children but that is a load of rubbish." He mentioned the thinking about vitamins being beneficial and said that it was "crap". If I had not had inner strength and knew that all babies need stimulation, my bright, sociable 7 year old boy, who is the centre of our family, could be seriously learning disabled.

Mother of 7 year old

When she was born we were told that she wouldn't be able to do anything apart from the washing up.

Mother of 27 year old

The consultant obstetrician, directly after Sarah's birth, commented to two junior doctors in my hearing that, "Perhaps ante-natal testing should be insisted on so that Down's babies weren't born".

Mother of 11 year old

Kimberley was born at 7.42 am . She was taken from me for her Vitamin K injection, nobody said anything. I asked to see her in the afternoon, she was brought to me but later taken back to be seen by the paediatrician. He then came back with her, plonked her on my tummy and said, "You have a Mongol".

Mother of 12 year old

The senior doctor who came to visit me the day I had my child with Down's syndrome was very cold and callous. My young daughter was sitting in the hospital admiring her new little brother. The senior doctor said that it was all very nice but I would have to bear the hassles of people being nasty to me. He said that people would look at the baby in the pram and have to look away in horror. My daughter cried her eyes out, she was too young to understand and wanted to know why people would look in horror. Luckily I had a very strong bond with my baby by then, but what a thing to say to new frightened parents! This has always stayed with me and I will never forget his attitude. Nothing like that has ever happened.

Mother of 14 year old

Our paediatrician has never given us anything positive to look at. She has basically told us that he will not amount to anything and be a burden to us throughout our lives. We know that this is not the case.

Mother of 18 month old

While in hospital the consultant who told us that our son had Down's syndrome told us "Not to expect anything as he won't be able to do anything". Shortly after he came out of hospital the midwife called out our GP as he had a sticky eye. On his arrival he said to me, "So I understand he has some form of mongolism." When our son was 2 ½, I was informed by the consultant, "There is no point in working your guts out to help him because he will never be normal". I realise these incidents are not examples of the medical treatment my son has received, but examples of attitude shown towards him by some members of the profession.

Mother of 7 year old

We were very badly treated when he was born. We were told he was a rag doll and would be good for nothing.

Mother of 9 year old

When first born we were told by a doctor that it would have been better if she had died at birth.

Mother of 17 year old

When he was born we were told that our baby was not good enough to love and take home. It was really awful and even now this still stays with us.

Mother of 10 year old

When he was born we were told to go home and have another baby, we could leave him at the hospital if we wanted to.

Parent of 10 year old

I was advised to have my son fostered or adopted when he was 3 months old as he wouldn't amount to anything, that it was best to try again for another baby. When my son was 12 months old I asked the health visitor what I thought was a perfectly normal question - when

should I start thinking about potty training. She told me that she felt I had not accepted my son for what he was and went on to say that no doubt when he was older I would be asking about A-levels. Later, when I enrolled my son at the local play group a doctor told me again "that I had not accepted that she wasn't normal". She felt that he was spoilt and needed a few sharp smacks on his bottom and he would soon learn who is boss. I feel that my son is continually having to earn what others have automatically as their right.

Parent of 13 year old

The treatment, understanding and care we received when our son was born was disgusting. I will never forgive or forget the nightmare we had in hospital.

Parent of 10 month old

When he was born the shock of him having Down's syndrome was made greater by the appalling insensitivity of the hospital staff. However, we were determined to do everything in our power to enable our son to lead a 'normal' life. This has not been easy, our health visitor had no knowledge or experience of Down's syndrome, our GP told us "how wonderful we were to bring him home".

Parent of 21 month old

We were given the diagnosis 10 days after her birth. A paediatrician broke the news to us. No counselling was offered and he told us, "You have 15 minutes to pull yourselves together and I'll see you again in 2 months' time". He then sent us home with a handful of leaflets. I still have a gut feeling that the hospital knew that my daughter had Down's syndrome but never said a word. A nurse kept coming "to have a chat", she kept asking what we would do if our baby had Down's syndrome and would my husband leave me if she did.

Mother of 19 month old

Shortly after his birth a midwife told me that had she known she was carrying a child with Down's syndrome she would have had an abortion.

Mother of 11 year old

They seemed to be waiting for us to "break down" and were unable to understand that while he was not exactly what we had hoped for we certainly viewed him as our son and wanted him as part of our family.

Father of 1 year old

When my son was born I was put in a single room. This was known to have been occupied before by babies with disabilities. I was lonely, depressed and left alone most of the day except for routine observations daily. Instead of more attention I felt I got less. But then I knew I was having a baby with Down's syndrome so it shouldn't have been a shock. It was!

Mother of 9 year old

I would like to tell you how I was treated when I was carrying my daughter. I was under the care of two hospitals. I was told by one that my daughter had Down's syndrome and very bad abnormalities. I was advised that I should consider a termination as my child would not have a quality of life. This was all told to me over the telephone which was very distressing.

My husband and I decided to carry on with the pregnancy. At 30 weeks I was told that my child would need to be born by caesarean section within 2 days. The hospital I went to did not have a special care unit for babies so the maternity staff had to telephone all the hospitals with special care. None of them wanted to accept me as I was having a baby with Down's syndrome with abnormalities. My consultant rang another consultant and persuaded them to take me. My baby was born at 11lb/2oz with a slight heart murmur and no abnormalities.

Mother of 11 week old

When it was discovered that the baby I was carrying had Down's syndrome and a duodenal atresia (6 weeks before she was born), one doctor suggested that we withhold permission for the operation that was essential to save her life.

Mother of 9 year old

The Down's Syndrome Association calls for the implementation of the existing guidelines in all maternity units in the UK.

The Down's syndrome Association asks for assurance that parents who decline testing in pregnancy, or continue with a pregnancy when a diagnosis of Down's syndrome has been made, are treated with the same dignity and respect as other parents.

Reference: Cunningham, C C, Morgan, P, & McGucken, R B (1984), *Down's Syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? Developmental Medicine and Child Neurology*, 26, 33-39.

The M-word

When in 1866 John Langdon Down described individuals with learning disabilities, he adopted his classification from a dissertation by Blumenbach who described the divisions of the human race as Caucasians, Malay (Native American), Ethiopians (African), and Mongolians. Although his clinical description of persons with Down's syndrome was accurate, his theory that they resembled the Mongolians and represented an arrest in ethnic development was later interpreted as a racial insult. This theory was discarded long ago but was the source of the term *mongoloid* that was adopted for people with this syndrome. The term was dropped by the *Lancet* as long ago as 1964, the World Health Organisation banned its use in its publications in 1965, and the *Index Medicus* finally caught up with other medical opinion in 1975.

The description 'Mongol' was felt by parents to be so offensive, that in 1985, the Down's Syndrome Association mounted a poster campaign featuring two children with Down's syndrome, Sarah and David. The captions read, "Sarah has just learnt to say 'Hello'! Can you stop saying 'mongol'?" and "You call him 'mongol'; We say Down's syndrome; his mates call him David."

It is shocking to learn from the survey that even in the late 1990's, medical professionals still insist on using this insulting and racist terminology.

Parent of a child of 4 ½ years:

When Helen was first born we had an unfortunate episode with one nursing sister who called Helen a 'Mongol' and was very rough with her when taking blood, holding her virtually upside down and calling her an uncooperative baby.

Parent whose child is now 11 ½ years:

The first visit from a health visitor on our return home from hospital – she used the word "Mongol".

Parent of a child who is now 7 years old:

When Adam had his operation (at age 2) a young doctor said to a nurse when talking about Adam "It's that wee Mongol boy over there" (He didn't know we were within earshot).

Parent of a child who is 11 years old:

My gold award for ignorance goes to the Health Visitor who, looking at Gareth for his 6 month clinic check-up said "It doesn't look too obvious on his face, so he probably won't be a low grade Mongol."

One parent whose child is now 2 years old:

I did come into contact with a locum doctor at our surgery, who when I walked in said, "Ah! A Mongol child, you know they used to live in institutions years ago!".

Parent of a young man of 24:

I took Jonathan to a locum G.P. to have a boil lanced – his first remark as we went into his room, "Well, he's obviously a Mongol." This is only 2 years ago!

This parent's daughter is now 15 years old:

When Fiona was a young baby I wasn't coping well with the fact my father was very ill with terminal cancer. The G.P. came to my home and his response toward me was along the lines, "What do you expect to feel – your father has cancer and you have a Mongol with a heart defect who could die at any time."

The parent of a baby who is now 11 months old reported:

A former G.P. insisted on relating a 'humorous' tale about Mongols to me and also scare stories on the health decline of 'these children'

One parent told how at her baby's six-week check the doctor said,

We in the medical profession refer to them as 'Happy Idiots' and I see another little boy who's a Mongol.

A parent of a 6 year old girl wrote:

During an eye examination, the consultant repeatedly referred to Lucy as a 'Mongol' despite my asking him not to. He claimed it was a medical term. I wrote to the hospital and complained.

The mother of 22 month old Aymee wrote:

Our only criticism relates to a female doctor who continually referred to Aymee as a 'Mongol'. This we found to be totally unacceptable, plus her total putting down of Aymee having any chance of leading a near normal life.

Gabriel is now 9 months old. His mother wrote:

From our experience so far Gabriel has been treated extremely well by any health professionals we have encountered. However, we were amazed and shocked to discover Gabriel's computerised medical records described his special need as 'Down's syndrome/Mongolism'. When we approached our GP about this slang, non-medical term, we were told that they were unable to alter the screen as it was built into the program. We are still pursuing this with the surgery.

"He'll never join the army"

The following comments made by health professionals speak for themselves considering that most of them were unsolicited and came out of the blue.

"Most people think babies with Down's syndrome are horrible, but I think they're nice." – Nurse to mother of baby now 20 months old.

Senior audiologist, who sees a number of children with Down's syndrome, to mother of new baby (now 10 months):
"So is she mentally retarded?"

Mother of Daniel (now 16 years old): Daniel had a Health Visitor who wasn't particularly kind regarding his Down's syndrome and heart problem. A frequent comment from her was, ***"He doesn't look well, I shouldn't think he'll last the week."***

Daisy is now 24 months old. Her mother reported, ***My own G.P. ignored our daughter (who was beaming at him from her chair and aged 1 year). When I commented on her smile – still without looking at her, his reply was, "Yes, they do tend to be happy".***

Tilly is now 10 months old. Her mother reported being told, ***"She'll never develop more mental ability than a 5 year old and she'll have a hysterectomy when she is 14."***

Jack's parents have often felt patronised the health professionals, ***"He'll never be a brain surgeon"*** (comment made by a paediatrician). Jack is two years old.

Tom is now 13; when it was discovered that his eyesight was very poor, the ophthalmologist said, ***"We won't bother with glasses as he's not what you would call university material."***

Another ophthalmologist stated to the parent of Stephen (aged 11), ***“The problem with these children is they are either hyperactive or pathetic.”***

“There won’t be many like Luis when he’s older because so many more people terminate these days.” (Luis is two years old).

A Parental Skills Midwife told one parent, shortly after the birth, ***“Some people would say that it was the result of bad sex, but I don’t really hold with that opinion.”***

Martha is nearly three years old. Her mother wrote, ***Some health professionals seem to still be of the strong opinion (freely given) that Martha should not be integrated at mainstream school!***

Thomas’s mother was once asked by an ophthalmologist, ***“Why on earth didn’t you have an amniocentesis?”*** (she had!)

“It doesn’t matter - she has Down’s syndrome”

More than half of people with Down's syndrome have significant hearing problems, and problems with vision are at least as common. The problems which commonly occur are not unique to people with Down's syndrome, they can occur in any group of people, they just tend to occur more often and sometimes to a more marked degree.

Help for vision and hearing problems is available through surgical intervention, glasses, hearing aids and other techniques and is offered routinely to other groups of people.

People with Down's syndrome can gain physical and mental skills throughout their lives but the average rate of progress is slower than in other people. It is therefore imperative that hearing and visual problems are recognised and treated rather than becoming further obstacles to full development.

It is therefore disturbing to read in the survey responses that intervention is being denied or deemed unnecessary in so many instances.

We feel the ENT consultant blames any hearing and ear problems on our daughter having Down's syndrome. He seems to consider it to be something we will have to get used to and does not see her as a person.

Mother of 11 year old

An eye specialist recently told me that my daughter needed glasses "but with her condition one would not be able to tell if there was any improvement in her sight."

Mother of 6 year old

An ear specialist once told me that as my daughter has Down's syndrome she must be deaf.

Mother of 6 year old

He needed an eyesight test and was given the appropriate pre-test drops. However, because he was afraid of the darkness of the test room he was told to come back because he was awkward. We saw an eye consultant who had no patience at all. The actual content of the

test was far too advanced for a child with learning disabilities - letters of the alphabet, numbers, abstract pictures. He was only 4!

Parent of 8 year old

At the eye clinic, at the age of 4, the consultant referred to him as a baby, which I found offensive especially after sitting in a corridor for 2 hours waiting to see him and my son understandably being very het up and bored.

Mother of 4 year old

I have been told by his audiologist that if hearing problems develop he will not be offered grommets - he has Down's syndrome.

Mother of 3 year old

My son was initially refused spectacles because "he wouldn't need to see as well as other children".

Mother of 6 year old

Our local eye specialist could not test my daughter's eyes "because she could not read".

Mother of 20 year old

I was asked by an ENT specialist how I thought my son's life could be improved by his hearing increasing.

Mother of 16 year old

Since moving to the UK, we have been repeatedly told that grommets are rarely inserted in "Down's kids", as they never have normal hearing anyway.

Mother of 5 year old

I was sure he had a problem with his ears but the doctor refused to even look until I made threats. Then he looked and found fluid in his ears.

Mother of 17 year old

The ENT consultant made sweeping generalisations about hearing problems in people with Down's syndrome - " They all suffer from hearing loss in middle age".

Mother of 8 year old

One doctor refused to operate on my son's eye, saying if he rubbed or touched it, it would ruin it. But he had the operation done by another doctor and he has not touched it.

Mother of 26 year old

An eye doctor was unsure of sight loss and said to a nurse in front of me - "never mind, it doesn't matter - she has Down's syndrome."

Mother of 17 year old

After an eye test when it was decided that my son may need to wear glasses, the consultant said " Oh, he's Down's syndrome, they're usually placid so he may as well wear the glasses". I

felt that this was a stupid remark for anyone to say, especially a consultant. It is also completely untrue as he refuses to wear them and has broken them twice.

Mother of 3 year old

The Down's Syndrome Association demands that no person with Down's syndrome should be denied treatment on the grounds of their condition. Refusal of treatment would render the hospital open to action for negligence.

“What do you expect with a baby like that?”

One of the most common complaints expressed in the replies to the question **“Have you ever had any other difficulties getting medical help for the person in your family with Down’s syndrome?”** was that children/young people with Down’s syndrome were not treated as individuals by members of the medical profession.

Joshua, now aged 4 ½, kept getting bad colds, chesty coughs and was very pale and crying. The local GP said it was normal for a baby with Down’s syndrome. At 16 weeks he was in intensive care with bronchiolitis and pneumonia.

Ellie, who is now just over three, has, always been treated as a ‘Down’s child’ by the medical profession and they always say, ***“That’s what you expect with a Down’s child”*** or, ***“Down’s children do have this weakness.”***

Once, when Adam (age 11) was in agony because for some reason he could not urinate, he was screaming and rolling around in agony, the doctor asked whether he was in pain, as if he was an alien. Adam’s mother.

When James was 2 ½, hearing and sight problems gave rise to comments from professionals that, ***“it didn’t matter as he was mentally handicapped anyway so it didn’t matter if he could see or hear properly.”***

Emma is 12 years old and has alopecia (hair loss). The dermatologist said, in front of Emma, ***“It’s a side effect of Down’s syndrome. Nothing we can do; no idea why it was triggered. She can have a wig; luckily people with Down’s syndrome enjoy wearing wigs.”*** He spoke to me not her. She was in tears and hates her wig. He did not give her any routine tests re. hair loss (e.g. thyroid function, diabetes etc.) as is usual – he refused to test the urine sample brought in.”

Tilly is now 9 months old and has a small hole in her heart. Her parents reported: ***When she had a chest infection, we were told there was nothing wrong, as all children with Down’s syndrome wheeze and cough. We immediately saw a second doctor who gave her antibiotics.***

Matthew’s mother wrote: ***I am just reminded of an occasion when Matthew was about eleven. The consultant proceeded to examine Matthew’s ‘bits and pieces’, as he put it. Matthew was extremely taken aback and told him it was private. There was no prior request or explanation and his reply was “I’ve just got to see you’re all in order down there.” I did wonder whether the consultant would have got away with that, or even attempted it, had Matthew not been disabled. There is a lot of this kind of discrimination and undignified behaviour, I find.***

When Daniel had his first heart operation he was in a lot of pain. We were told by staff when we asked for pain relief, “Oh, he has Down’s syndrome; they don’t feel any pain.”

Daniel is now 8 years old.

Last year I took Sophie (aged 10) to my local GP’s surgery on a number of occasions. Each time, with barely examining her, they dismissed her symptoms as constipation saying most people with Down’s syndrome get constipation. I insisted there was something else wrong and that she’d never suffered from constipation in her life.

She became critically ill and we took her to A&E, the outcome being that she had a burst appendix and for several months had displayed classic symptoms.

One parent whose daughter is now 10 years old wrote, *When my daughter was 5 years old one senior consultant assumed she'd be in nappies for life. He also said, "all Down's syndrome children grow large (fat) and always pull things off!" (referring to any surgical appliances).*

It has become apparent to us over the years that there is a general reluctance on the part of many health care professionals to fully understand and treat with sympathy and interest the needs of our daughter, aged 16. There has been far too much of the approach from them that because she has Down's syndrome, this or that ailment is to be expected and not much can be done. This is almost always inherent and coupled with a patronising attitude. Rhian's father.

Professionals don't bother to communicate with him and decline to discuss things with us or gloss over particular concerns. He is due the same courtesies as everyone else, e.g. hello, goodbye, please, thank you. He is not a fool; he just has Down's syndrome. They also refer to him as 'suffering' from Down's syndrome or ask whether there are any health problems other than Down's syndrome. Surely children with Down's syndrome don't suffer; they are born with this disability and health problems are incidental to it. Down's syndrome should not be categorised as a health problem per se. Mother of Eliot, 1 year old.

Colin is nearly 15. His mother wrote: *Colin fell and fractured his neck of femur. He was in a great deal of pain, vomited, incontinent and obviously shocked. We waited two hours in A&E, despite my complaints. They didn't spot the fracture on X-ray, said he had just bruised himself. A physio tried to make me get him to walk. It was two weeks before they noticed the fracture and this was only because I refused to accept that he hadn't injured himself and leave. He did then receive prompt treatment. I am sure that because he has Down's syndrome they felt he was exaggerating the pain and he had two weeks suffering because of this.*

For two years prior to being diagnosed with diabetes, Susan was not well, having frequent 'hypo' type incidents, and severe tiredness. During this time she was never tested for diabetes. It wasn't until she presented the classic symptoms that she was diagnosed and treated. I believe, but can't prove, that she was diabetic during this time, and had she not had Down's syndrome, may have been treated differently. Susan is 33 years old.

Attended casualty with abdominal pain, but doctor was more interested in Down's syndrome, which was completely irrelevant to the problem. Jan is 8 years old.

I feel that if the doctors at the hospital where Neil was born had done a simple X-ray as soon as it was known that Neil was not feeding properly and being sick as soon as he was fed, Neil would not have needed the last two operations he has had and would not still be suffering because of it. As it was it took until Neil was so poorly and was admitted to Manchester Children's Hospital before we found that he had a hiatus hernia. By that time, they said the damage had been done. The doctors at the first hospital kept saying that it was because he had Down's syndrome and his stomach muscles were weak.
Neil is 16 years old.

Human Rights

Some members of the medical profession seem to think they are justified in assuming that parents do not really want their children. They cannot understand that parents love their children Down's syndrome and all. Under Article 2 of the Human Rights Act 1998 (to be implemented in 2000), which states **"Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a Court following his conviction of a crime for which the penalty is provided by law"**, such assumptions will be open to challenge.

Our son was described by a Senior Physician as "an unacceptable burden on resources medically, socially and educationally." Father of an 8 year old boy.

Elanor is now six and had an operation to repair a heart defect at 5 months. Her mother reported: ***The option not to operate and allow her to die was mentioned, so that we may start our life again!***

At 10 weeks of age Peter was in ITU on a ventilator because of severe bronchiolitis. I was asked if I really wanted the treatment to continue or would I like them to 'stop trying'. Mother of Peter now 10 years old.

The first time Lucy had an operation for grommets and adenoids, she wouldn't come round from the anaesthetic and started to inhale blood. When everyone was rushing and panicking I did too. I was asked if she was my only child. When I said "No, the sixth.", the nurse's reply was, "Well, she does have Down's syndrome. Why are you panicking?"

Parent of Lucy, now aged 13.

Zoe had breathing problems at birth and we were offered the option of taking steps to save her life (or not). Mother of Zoe, aged 2.

When Sarah was born in 1981, the attitude of the doctor in charge was "Leave well alone and let nature take its course." He had little experience or contact with children with Down's syndrome and a very negative and biased attitude towards both my daughter and me. However, to be fair, by the time we left that city in 1985, when my daughter was 3½, his attitude had changed. Mother of Sarah, who died of meningitis aged 14.

Article 3 of the Human Rights Act 1998 states that: **“No one shall be subjected to torture or inhuman or degrading treatment or punishment.”** Expert legal opinion suggests that this could be of relevance to disabled people who require treatment to maintain their well-being.

Chad’s behaviour can be extreme with head-banging, but he can sign very well. Most doctors and nurses are unable to communicate with him which causes him to become frustrated and some nurses haven’t the time for him. One doctor stabbed Chad six times in order to get a line in him. Both Chad and myself were understandably very upset. He ended up with one in his head! This doctor was very short when we asked him to stop.

Chad is 5 years old.

Usually treated like any other person. I have only one complaint. When Lisa (aged 12) was investigated for urine infections, the consultant did not believe me when I said Lisa would not co-operate when having a catheter inserted into her bladder. I asked if a general anaesthetic was possible and was told it was not. Two attempts were made (each took a whole day on the children’s ward). The second time large doses of sedative were administered, and a catheter eventually put in place, after much distress to Lisa. If only they had listened to me, her mother, I believe all that could have been avoided. Lisa is now 16 years old.

Martin had a lump of glass in his foot once. When the doctors finally decided to remove it, I had to help hold him down on the table, which I found upsetting. He had people holding down his arms and legs and the glass was pulled out of his foot, but no numbing lotion was applied so it must have been a really painful experience for him. Martin is now 13 years old.

At the moment I have just changed doctors. Because my old doctor would say that there was nothing wrong with Stephen when I knew there was. In my opinion with some doctors it is a case of get them in and get them out as quickly as possible. On one visit he was told to soak his feet in a bowl of bleach and water to cure his eczema. Stephen is 20 years old.

Daniel was admitted to our local hospital with breathing difficulties. I stayed with him, but as he was an emergency admission I could not let my husband know what had happened. So I asked to go home to ring my husband. I could not do this from the hospital as my husband works abroad. I was assured no treatment would be given, and, while I was away, a nurse would sit with Daniel until I returned in about 45 minutes. Before I went back I rang the ward to see how Daniel was. I was told he was now calm. When I walked into Daniel’s room he was sitting in his bed sobbing. He had seven plasters on his hands and arms. I was told he was very difficult when they tried to take blood. Seven people were needed to hold him down – he was terrified. Daniel is still frightened of nurses and hospitals.

“They kept telling me she was doing fine”

About one in 3 children with Down's syndrome are born with a heart defect. Some heart defects are quite minor, such as a heart murmur and some are severe, requiring medication and/or surgery. In the first few weeks of life symptoms and signs may be absent or minimal despite the presence of significant congenital heart disease. Since the majority of defects are surgically

treatable with a good prognosis it is essential to make the diagnosis before irreversible changes occur from pulmonary vascular disease. It is therefore essential that an echocardiogram is done as soon after birth as possible. This is the only test that can provide an accurate diagnosis.

When our daughter was born she was not checked for a heart condition. I believe she had her first heart attack when she went into hospital for cataracts when she was a few weeks old. When we moved the clinic here was surprised that no tests had been done. So aged 3 ½ she was sent to London for catheterisation. It was discovered it was too late to operate. We were not even given the option or choice.

Mother of 15 year old

They were quick to assume that his snuffling and fast breathing were because of small tubes - in fact it was heart failure.

Mother of 7 month old

I find it annoying that her heart problems cannot be rectified while she is young. Why do we have to wait? Others appearing to have similar problems have surgery when they are young. Why not our daughter?

Mother 23 month old

I feel that my daughter should have had her heart echo done as near to birth as possible. This is the only test that can detect accurately if the heart is normal. My daughter had a cardiogram and her heart listened to on numerous occasions but her hole was so big it could not be detected. She had numerous symptoms to show she had a heart condition but none of the doctors picked up on these. I am not a doctor so I just trusted their judgement. I wish I could help any parents with babies with Down's syndrome to make sure this test is done as early as possible. My daughter is now doing really well but if it had been found sooner she would have had a much easier start in life, and had a speedier recovery from the surgery.

Mother of 1 year old

Heart related problems often occur in babies with Down's syndrome, yet my daughter was not scanned prior to leaving hospital at birth. At 10 days old she had an apnoea attack and was rushed to hospital!

Mother of 4 year old

Until I moved, when my daughter was 3, I was told that her heart was fine except for a murmur. When I moved I took her to the GP on several occasions with chest infections pneumonia, collapsed lung etc., etc. I was seen by a locum doctor on one visit and he advised that I see a heart specialist immediately who in turn performed open-heart surgery within a fortnight. I thank the day my daughter was seen by that locum doctor.

Mother of 13 year old

Our son had an abnormal chest x-ray at birth, which was ignored. He had an enlarged liver at 4 months, mild heart failure. We were told at this check up that his heart was perfectly normal. When he was 8 months old he was admitted to hospital with severe pneumonia, severe heart failure and pulmonary oedema. The same consultant told us that we had a choice of transferring him to the intensive care unit to try and save his life, but "because he has Down's syndrome and is mentally handicapped" he asked us if "we wanted to leave him to slowly slip away".

Mother of 7 year old

He was treated as being asthmatic because a previous doctor had diagnosed this. Actually he had heart failure and a hole in his heart.

Mother of 10 year old

We were originally told that he didn't have a heart murmur so his heart was therefore normal. The cardiologist told us that the hole was so large his lungs would have compensated at birth and therefore there would be no murmur.

Mother of 7 year old

She was being monitored by a heart surgeon who kept telling us she was doing fine. It was her paediatrician that alerted me to surgery being necessary. It had never been mentioned to me before. At the next appointment I verbally attacked the heart surgeon for his lack of openness and insisted on severing all consultations with this particular doctor.

Mother of 19 year old

My son was seen at 2 weeks old in April 1996, he had 2 holes in his heart and an open duct. His breathing was noisy and his weight gain was slow, he was also very floppy. The health visitor was concerned about his blue feet and hands. When I asked the consultant paediatrician about these things he reassured me that it was all part of his Down's syndrome. In October 1996 I saw a paediatrician and asked about the holes in his heart. He listened with a stethoscope and said that as he could not hear anything they must have closed. I explained that no doctor had ever heard his heart problem, but it had been picked up by a scan. I asked for another scan to prove that they had closed but never heard anything. In the December a new health visitor was concerned that no referral had been made. In March 1997 I received a referral letter. This was too late. In September 1997 aged 17 months and weighing just 17lbs he died. He was a very special beautiful boy who should not have died. I have met children with Down's syndrome with similar conditions who were treated and are now living.

Mother of 17 month old (deceased)

We had to wait 4 months for an echocardiogram.

Mother of 20 month old

Our daughter's heart problem was not found until she was two years old which we found strange as so many children with Down's syndrome have some form of heart defect. Then we were told it was too late to operate.

Father of 10 year old

When she was born we were refused a heart scan even though she had a murmur and I had requested one. I was told that parents of children with Down's syndrome fuss too much and that as the consultant he knew best!

Mother of 6 year old

I was concerned that the pneumonia was better but she continued to have cyanotic spells. I was told - "What do you expect, she has Down's syndrome, children with Down's syndrome are allowed to go blue".

Mother of 2 year old

The initial cardiologist told us "blueness was a feature of Down's syndrome".

Mother of 4 year old

The heart specialist was dismissive and I was given the impression it would be a waste of money to do any further tests other than the ECG.

Mother of 20 year old

Heart Surgery

Research dating back as far as to the early 1970's has shown that when comparable cardiac care is received (age of diagnosis and timing of surgery) both children with Down's syndrome and other children with similar heart defects have similar surgical outcome. In fact in children with complete atrioventricular septal defect (avsd or av canal), the surgical outcome of children with Down's syndrome seems better compared to other children.

In spite of this certain cardiac teams in hospitals in the UK have ignored this evidence.

Many respondents to our survey felt uneasy about the advice they had been given, sought a second opinion and were able to obtain the appropriate medical intervention for their children.

Many parents/carers trusted the judgement of the paediatric cardiologists and now question whether they were wise to do so.

The impression we have gained is that some hospitals in the UK still see Down's syndrome as a reason to delay or refuse surgical intervention.

I was told by our original paediatric consultant that it would cost at least £10,000 for heart surgery and that they would rather spend that sort of money on a 'normal' child.

Parent of 8 year old

The hospital refused heart surgery, their explanation was that my daughter was terminally ill and perhaps may only live to the age of 5. I had to shop around and it was only after requesting a second opinion that we were offered surgery at another hospital. If I had not had a second opinion my beloved daughter would be dead by now.

Mother of 8 year old

The consultant paediatrician treats him as a thing with Down's syndrome rather than a little boy with heart trouble.

Mother of 2 year old

We were told that her condition was inoperable and she was given 5 years to live at the age of 17. When we were finally told an operation was possible the cardiologist said that with people with Down's syndrome they preferred not to operate, but to let nature take its course.

Parent of 26 year old

I was told by another medical professional that surgery should have taken place to repair her heart condition. When I confronted her doctor I was told that "her quality of life" did not warrant such surgery. Surely doctors take their oath to care for others. So why, when they come across someone a little different, do they think they have the right to withhold treatment? I used to use the expression "Playing God", but they are not, because God sent her warts and all. In fact, I suppose you could say they are playing "Devil's Advocate".

Mother of 17 year old

A newly qualified doctor at our medical practice was surprised that our child had been given the heart operation - because she had Down's syndrome!

Mother of 4 year old

We were told that our son's heart condition was inoperable. We now know this to be untrue.

Mother of 17 year old

When my daughter was six weeks old it was discovered that she had a heart defect which seemed more severe than it turned out to be. I had an extremely upsetting consultation with a heart consultant who seemed to be saying that she needed an operation but there was not going to be one. I was on my own with my daughter facing 4 doctors of varying levels of seniority. I was in tears but no one offered to comfort me. When they left, one of them, an extremely compassionate paediatrician came back and was kind to me. She explained that they did not operate on people with Down's syndrome in that health authority and she felt that a need for an operation had been exaggerated. This was 20 years ago - I hope things have improved!

Mother of 20 year old

They told me an operation would do no good. It makes me angry now as they are doing all sorts of operations. She passed away three years ago now, aged 25. We all miss her very much and wish she was still here.

Mother of 25 year old (deceased)

The surgeon was patronising, disinterested and deliberately rude when her father and I asked about the appropriate treatment for her heart condition. Treatment was not offered at this hospital. We were told there was nothing that could be done. Another parent persuaded us to get another, less biased opinion.

Mother of 12 year old, surgery performed at another hospital.

On our first visit to the senior surgeon we were greeted with "Do you realise that if he survives the operation he will probably outlive you". We replied that we hoped he would and his reply was, "He will probably end up in an institution". He went on to tell us that he could probably enjoy a reasonable childhood without an operation. He did accept our son for surgery but by the age of 15 months another cardiologist felt it was unlikely the operation would be done before 2 years of age. In spite of letters to our MP and the health authority he did not seem to be getting any nearer the top of the list.

Mother of 9 year old eventually referred to another hospital where successful surgery was performed.

Looking back we sometimes wonder if economy came into decision making about not recommending surgery - but I hope we were right to trust our paediatric cardiologist

Mother of 19 year old

The first consultant we saw said the hole was so small it didn't need closing. A year later, by chance, we saw another consultant and he talked about having the hole closed and all the problems that would possibly arise if it were not. I feel the first consultant thought - he has Down's syndrome, it's not worth it!

Parent of 7 year old

In the early years I wondered whether he would have been operated on to close his ASD, if he had not had Down's syndrome, but I couldn't prove it.

Mother of 23 year old

The seriousness of my daughter's heart problem only came to light when she was 7 despite regular heart scans. Surgery was refused by first cardiologist we saw in London who said that it would not benefit her because of the lung damage he assumed was present. He also said that the operation itself would be very risky. We could not fully accept the prognosis given by the London cardiologist, as she had never shown symptoms of a major problem. We sought a second opinion privately with a cardiologist who was much more sympathetic. After extensive tests his team concluded that her lungs would withstand surgery and that it would benefit her. Three weeks later she had very successful surgery.

Mother of 11 year old

We believe we were not given the correct information about her heart defect in terms of going ahead with an operation.

Mother of 8 year old

The diagnosis we received from the cardiologist was different to that of our local hospital. We were told he would need surgery at 4 or 5. If we had waited until then he would not have survived. This would have been a dangerous delay. The cardiologist saw the Down's syndrome more than the heart problem and therefore put less value on my son's life. It was as if, 'What did heart surgery matter he would still have less value because of his learning difficulties?'

Mother of 3 year old, second opinion sought at another hospital and successful surgery undertaken.

In 1992 we were advised against the surgery by a cardiologist in London, saying that, "She would have a good few years of life" and we wouldn't have to worry about going through this. We later read his published views that he didn't believe in prolonging the lives of disabled people. We insisted a second opinion and were told that her heart could be repaired.

Mother of 6 year old

"It should be clear that neglect of the patient with Down syndrome and cardiac disease is not prudent. Patients who survive with complete atrioventricular canal and pulmonary vascular obstructive disease are significantly worse off than their peers who have received treatment... in their early 20's, these children often must use a wheelchair, are persistently short of breath, cyanotic¹, and polycythemic². They may develop right cardiac failure. Clinical manifestations of their chronic hypoxemia³ include visual disturbances, severe headaches, dyspnea⁴ on any exertion, chest pain, syncope⁵, cardiac dysrhythmias⁶, and, in some cases associated bleeding tendency. There is no doubt that the quality of life in the unoperated patient who develops pulmonary vascular obstructive disease is poor."

Gordon LS. Cardiac Conditions. In: Van Dyke DC, Lang DJ, Heide F, van Duyne S, Soucek MJ, eds. *Clinical Perspective in the Management of Down Syndrome*. New York: Springer -Verlag, 1990: 55-71

¹ Blue colouration of skin and lips owing to a lower amount of oxygen in the capillaries

² Increased number of red blood cells

³ A condition where the blood contains too little oxygen

⁴ Breathlessness

⁵ Loss of consciousness related to lack of blood flow to the brain

⁶ Disturbance of rhythm

Heart/Lung Transplant

For many people with Down's syndrome with inoperable heart conditions, the only possible course for survival is a heart/lung transplant. In the UK people with Down's syndrome are denied this treatment because it is felt that their lives are of less value. Article 2 of the Human Rights Act states – **“Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a Court following his conviction of a crime for which the penalty is provided by law”**. The Human Rights Act takes effect in 2000 and this denial of treatment may be open to challenge.

If she needed a heart transplant I understand she would not get one.

Mother of 2 year old who had unsuccessful heart surgery. At present uncertain as to whether cardiac team will try again this year.

There is a problem about considering our children for heart/lung transplants. They will not do it.

Father of 15 year old with inoperable heart condition.

The Down's Syndrome Association recommends that echocardiograms be carried out in respect of all new born infants with Down's syndrome. Failure to do so would render the hospital open to action for negligence.

The Down's Syndrome Association demands that no person with Down's syndrome should be denied treatment on the grounds of their condition. Failure to do so would render the hospital open to action for negligence.

Conclusion

Three-quarters of respondents to the survey were satisfied with the treatment their family members with Down's syndrome had received at the hands of medical professionals. However, the Down's Syndrome Association considers that any level of discrimination against people with Down's syndrome is unacceptable. The figure of one in four who had experienced discriminatory attitudes is simply too high to be ignored. The Down's Syndrome Association demands that immediate action as set out below be taken to rectify this appalling state of affairs.

- Guidelines exist for medical staff to help them with the difficult task of telling parents that their child has Down's syndrome. The Down's Syndrome Association calls for the implementation of the existing guidelines in all maternity hospitals in the UK.
- The Down's Syndrome Association asks for assurance that parents who decline testing in pregnancy, or continue with a pregnancy when a diagnosis of Down's syndrome has been made, are treated with the same dignity and respect as other parents.
- The Down's Syndrome Association recommends that echocardiograms be carried out in respect of all new born infants with Down's syndrome. Failure to do so would render the hospital open to action for negligence.
- The Down's Syndrome Association demands that no person with Down's syndrome should be denied treatment on the grounds of their condition. Refusal of treatment would render the hospital open to action for negligence.
- The Down's Syndrome Association calls for medical students to receive longer training in learning disabilities, focusing on the social model and existing good practice.

The Down's Syndrome Association asks medical professionals to REMEMBER

- a. People with Down's syndrome are human beings deserving of dignity and respect.
- b. People with Down's syndrome are all individuals. Because they share a label does not mean that they share all the same characteristics. The same can be said of their parents.
- c. Do not use the racist term "Mongol". It is not a medical term and causes great offence.
- d. Do not ask questions that are not relevant simply to satisfy your curiosity or offer advice about non-medical issues.

Appendix 2

A special Down's Syndrome Association survey about the treatment of people with Down's syndrome by health care professionals

The DSA does not expect all doctors, nurses or other health care professionals to be experts on Down's syndrome. However, we do believe that they should approach the health care needs of people with the syndrome in exactly the same way as for any child or adult.

For example, they should be courteous and caring, they should try to inform themselves fully about any special medical needs associated with the syndrome, and they should ensure that all health care services are made accessible to people with Down's syndrome.

In this special DSA survey we ask you about the health needs of the person in your family with Down's syndrome and about how they have been treated by health care professionals.

Only complete this questionnaire if you are (or have been) responsible for someone with Down's syndrome and know about his/her medical history. Please answer all questions as clearly and as accurately as possible, giving the answers which you think best describe your experiences and views.

If a question does not apply to you, please put N/A in the space provided. If you need more space, use extra paper and mark clearly the question to which your additional information refers.

The completed questionnaire should be returned to the Down's Syndrome Association in the pre-paid envelope provided as soon as possible but no later than Tuesday 20th October 1998.

Many thanks for your time.

1. About yourself

1.1 Name:

1.2 Address:

1.3 Telephone number:

1.4 What relationship do you have to a person with Down's syndrome e.g. mother, father, grandparent, carer, etc.)?

2. About the person in your family with Down's syndrome

2.1 Name:

2.2 Sex:

2.3 Age:

2.4 Address (if different from your own)

3. About contact between the person in your family with Down's syndrome and the medical profession

3.1 What medical problems, if any, does he/she have? Please give brief details.

3.2 Has he/she ever needed any specialist medical help for any of the above problems? Please give brief details.

3.3 Is he/she currently seeing a doctor (other than a GP) for any of the above medical problems? If yes, please describe the treatment they are getting.

3.4 Has he/she ever had an operation for any of the above medical problems? If yes, please describe what the operation was when it was performed.

- 3.5 Has he/she ever had an operation or other treatment refused, delayed or cancelled? If so please give details including any explanation given by doctors.
- 3.6 Have you ever had any other difficulties getting medical help for the person in your family with Down's syndrome? If yes, please explain what difficulties you faced.
- 3.7 Have you ever felt that he/she has been treated less well by health care professionals because he/she has Down's syndrome? If yes, please explain.
- 3.8 Have you or any other member of your family ever sought legal advice or action over the medical treatment of the person with Down's syndrome in your family? If yes, give details.
- 3.9 If you wish to add any more comments about how the person with Down's syndrome in your family has been treated by doctors, nurses or other health care professional please include them here.

4. About the research we are conducting for a television programme.

As part of our campaign on medical discrimination and Down's syndrome, the Down's Syndrome Association is working with a television company with a view to producing a programme on this subject.

The programme will look into allegations of unfair treatment and would include comments from people with Down's syndrome and their families. As part of our research we would therefore like to contact some of the families who taken part in this survey. All contact will be in strict confidence. If you are happy to be contacted please tick the box below.

I am happy to be contacted about this survey

☐

Appendix 3

3.6 Have you ever had any other difficulties getting medical help for the person in your family with Down's syndrome? If yes, please explain what difficulties you faced.

In 126 replies to this question the particular area of medicine where difficulties occurred were cited.

ENT specialist (incl.Audiologist)	17	
Cardiologist	27	
Dentist		4
Dermatologist	2	
Endocrinologist	3	
Gastro/Intestinal	3	
General Practitioner	22	
Health Visitor	0	
Hospital Doctor+	15	
Immunologist	0	
Midwife	0	
Nurse	3	
Ophthalmologist	0	
Orthopaedic surgeon	6	
Paediatrician	6	
Physiotherapist	2	
Psychologist	1	
Speech Therapist	5	
All contact*	10	
Total	126	

+ Hospital Doctor most often refers to doctors working in A&E departments.

* Refers to contact with all types of medical professional.

3.7 Have you ever felt that he/she has been treated less well by health care professional because he/she has Down's syndrome? If yes, please explain.

In 255 replies to this question the health care professional who, it was felt, treated the person with Down's syndrome less well was cited.

Cardiologist	34	
Dentist		6
Dermatologist	4	
Endocrinologist	3	
ENT (including audiologists)	24	
Gastro/Intestinal	5	
General Practitioner	37	
Health Visitor	4	
Hospital Doctor+	28	
Immunologist	1	
Midwife	2	
Nurse	14	
Ophthalmologist	22	
Orthopaedics	5	
Paediatrician	18	
Physiotherapist	0	
Psychologist	1	
Speech Therapist	10	
All contact*	37	
Total	255	

+ This most often refers to doctors in A&E departments.

* Refers to contact with all types of medical professionals.

3.9. If you wish to add any more comments about how the person with Down's syndrome in your family has been treated by doctors, nurses or other health care professionals, include them here.

In response to this question 66 parents of a person with Down's syndrome expressed great dissatisfaction with the way they were first told about their child's condition.

Appendix 4

**PRENATAL TESTING AND SCREENING FOR DOWN'S
SYNDROME**

**A STATEMENT ON BEHALF OF THE DOWN'S SYNDROME
ASSOCIATION**

The Association accepts that prenatal testing for Down's syndrome is becoming a routine part of antenatal care. However, we strongly believe that any programme of testing for a genetic condition must be accompanied by non-directive counselling. Individuals can then make a decision based on full and accurate information. Appropriate support must be provided regardless of the choices made.

January 1997

Appendix 5

Disclosure of Diagnosis of Down's Syndrome - A Model Service

Parents to be told -

- 1. By a consultant paediatrician and specialist health visitor.**
- 2. As soon as possible.**
- 3. Together.**
- 4. With the baby present.**
- 5. Directly and with a balanced viewpoint.**
- 6. That the health visitor would see them again as soon as they wanted. (Practical advice/ contact numbers).**
- 7. The parents allowed privacy immediately after the interview.**
- 8 Follow up interview arranged 24 hours after disclosure.**

Cunningham, Morgan, McGuken 1984

Further Reading

DISCLOSURE & DIAGNOSIS

Breaking the News: *A Resource for Developing Guidelines in Good Practice, Procedures and Training in Informing Parents of Diagnosis of a Child's Impairment.*

North Western Regional Advisory Group on Learning Disability Services/ North Western Regional Health Authority 1992

Right from the Start: *Looking at Diagnosis and Disclosure - parents describe how they found out about their child's disability.*

Anne Leonard

Scope 1994

Making the Right Start: *The way parents are told about their child's disability.*

R Newton & S Lingham

Paediatric Practice Guidelines 1996

British Paediatric Association Standing Committee on Paediatric Practice Guidelines

Making the Right Start: *a practical manual to help break the news to families when their baby has been born with a disability*

Sheila Jupp

Opened Eye Publications 1992

Medical Care in Down Syndrome: *A Preventive Medical Approach*

Paul T Rogers & Mary Coleman

Marcel Dekker Inc 1992

Sharing the News: *a good practical guide and training pack for professionals working with Asian families when they are first told about their child's disability*

Robina Shah

Mental Health Foundation 1998

FOR PARENTS AND CARERS *Your baby has Down's syndrome* Sarah

Rutter Down's Syndrome Association 1997

The genetics of Down's syndrome - *information for parents and other carers*

Anna Kessling & Mary Sawtell

Down's Syndrome Association 1996

Down syndrome: *the facts*

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Mark Selikowitz
Oxford University Press 1997

Down Syndrome: moving through life
edited by Yvonne Burns & Pat Gunn
Chapman & Hall 1993

Facing the crowd: managing other people's insensitivities to your disabled child
Deborah Fullwood & Peter Cronin
Royal Victoria Institute for the Blind 1989

MEDICAL AND HEALTH INFORMATION

Ageing and its consequences for people with Down's syndrome Dr Tony Holland Down's Syndrome Association 1997
Atlanto axial instability - notes for parents and other carers Dr Jennifer Dennis Down's Syndrome Association 1995
Depression in People with Learning Disability
Defeat Depression
Royal College of Psychiatrists & Down's Syndrome Association 1996
Diabetes and Down's syndrome - notes for parents and carers Peter Selby Down's Syndrome Association 1997
Down's Syndrome and Alzheimer's disease - a guide for carers
Cliff Cunningham & Richard Marler
Down's Syndrome Association 1995

Eye problems in children with Down's syndrome - notes for parents and carers
Barbara Crofts
Down's Syndrome Association 1997

Gastrointestinal problems in children with Down's syndrome - notes for parents and carers
Dr Liz Marder
Down's Syndrome Association 1996

Hearing problems in people with Down's syndrome - notes for parents and carers
Dr Jennifer Dennis
Down's Syndrome Association 1995

Pre-natal testing for Down's syndrome
Mary Sawtell
Down's Syndrome Association 1996

Medical issues in Down's syndrome
edited by Dr Jennifer Dennis & Dr Liz Marder
Down's Syndrome Association 1995

Medical management of children with Down's syndrome

E Marder & J Dennis

Current Paediatrics 1997

(contact Down's Syndrome Association)

Thyroid disorder among people with Down's syndrome - notes for parents and carers

Dr Jennifer Dennis

Down's Syndrome Association 1995

Adolescents with Down syndrome- towards a more fulfilling life

Siegfried Pueschel and Maria Sustrova

Paul H Brookes 1997

Adults with learning disabilities- a practical approach for health professionals

Edited by Jean O'Hara & Anthea Springer

John Wiley & Sons 1997

Counselling in child disability - skills for working with parents

Garry Hornby

Chapman & Hall 1994

Down syndrome - advances in medical care

edited by Ira Lott and Ernest McCoy

Wiley Liss 1992

Down syndrome - a promising future together

Edited by Terry Hassold & David Patterson

Wiley Liss 1999

Down syndrome - the facts

Mark Selikowitz

Oxford University Press 1997

Heart Problems in Children with Down's Syndrome: a video for anyone involved in the care or treatment of a child with Down's syndrome and a congenital heart defect

Down's Heart Group 1998

Down's Heart Group Information Pack

Down's Heart Group 1998

Heart Children

Philip Rees, Adelaide Tunstill et al

Heart Line Association 1992

Medical and surgical care for children with Down's syndrome - a guide for parents

D C Van Dyke, P Mattheis et al

Woodbine House 1995

Minimising problems in eye surgery for adults with severe learning difficulties

Focus Fact Sheet

RNIB 1998

New approaches to Down syndrome

Edited by B Straford and P Gunn

Cassell 1996

Signposts for Success

The Department of Health 1998

The NHS - Health for all? - *People with learning disabilities and health care*

Roslyn Band

Mencap 1998

FOR CHILDREN AND ADULTS WITH DOWN'S SYNDROME

Going into hospital

S.Hollins, A. Avis, S Cherverton

Books Beyond Words

Royal College of Psychiatrists & St Georges Hospital Medical School 1998

Going to out-patients

S.Hollins, J.Bernal, M Gregory

Books Beyond Words

Royal College of Psychiatrists & St Georges Hospital Medical School 1998

Going to the doctor

S. Hollins, J Bernal, M Gregory

Books Beyond Words

Royal College of Psychiatrists & St Georges Hospital Medical School 1996

Down to Earth Pack

Down's Syndrome Association Spring 1999

Living with Down's syndrome

Jenny Bryan

Wayland Publishers Ltd 1998(Wayland publishers produce a series of books for children on living with certain health conditions, for example, Living with Asthma, Living with Diabetes, Living with Epilepsy)

The Healthy Way – *How to stay healthy – a guide for people with learning disabilities*
The Department of Health 1998

PERSONAL ACCOUNTS

Living in the real world

edited by Chris GoodeyThe Twenty-One Press 1991

Differences in common - *straight talk on mental retardation, Down syndrome and life*

Marilyn Trainer

Woodbine House 1991

(the term mental retardation is used in the United States. It is no longer used in the UK)

Spencer's Story

Bill & Mary Tutty 1999

(available from the Down's Syndrome Association)

Couples with intellectual disabilities talk about living and loving

Karin Melberg Schwier

Woodbine House 1994

Uncommon fathers - *reflections on raising a child with a disability*

Edited by Donald J Meyer

Woodbine House 1995

A minor adjustment

Andy Merriman

Macmillan 1999

SOCIAL RESEARCH

New approaches to Down syndrome

Edited by Brian Stratford & Pat Gunn

Cassell 1996

Down's syndrome: *children growing up - longitudinal perspective*

Janet Carr

Cambridge University Press 1995

Families and their children with Down's syndrome - *one feature in common*

Elizabeth Byrne, Cliff Cunningham, Patricia Sloper

Routledge 1988

Working with parents: *frameworks for collaboration*

Cliff Cunningham & Hilton Davis

Open University Press 1985

The silent minority - *children with disabilities in Asian families*

Robina Shah

National Children's Bureau 1995